Risks Associated with Genetic Testing: Health Insurance Discrimination or Simply Business as Usual?

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Abstract

Doctors can test patients for mutations that put them at high risk for hereditary forms of such diseases such as breast and ovarian cancer. Even though the numbers of opportunities for disease prevention using genetic testing will increase with time, the risks of testing, which include insurance loss and employment discrimination, currently make testing problematic. Many people would like to have use of genetic information in health insurance underwriting made illegal. But it is hard to imagine in the current system of risk-based underwriting that insurance companies will willingly forego access to a growing body of information on risk. If the American public chooses to limit the use of genetic information, a reassessment of current laws or methods of paying for health care will be needed.

Recent advances in molecular medicine have enabled doctors to identify mutations that put people at high risk for such diseases as breast and ovarian cancer. [1,2] But the value of genetic information is questionable when there are no proven interventions, and there is a risk of insurance loss, employment discrimination, psychological harm, or harm to relationships.

As evidence that such interventions as prophylactic surgery reduce morbidity and mortality accumulate,[3,4] the need to eliminate the risks associated with testing will grow. Most efforts to eliminate adverse effects of genetic testing on insurability have taken the form of proposed laws that would exclude use of genetic information in assessing a person's risk for disease. The use of risk assessment to determine insurance rates is commonly referred to as underwriting, and it ultimately determines who will have access to health care. Given the current system of underwriting, it is difficult to exclude genetic information from risk assessment. This is because genetic information includes not only the results of DNA testing, but such other information as family history, which is already used in underwriting for certain kinds of insurance.

As genetic information becomes useful in decision making, more questions arise. For example, is it worth risking the loss of insurance to find out whether prophylactic surgery is warranted? What protection from loss of health insurance or from prohibitive increases in rates exist to enable patients to obtain genetic information for making medical decisions? What protection is needed? And what is really possible in our current health care system?

Lack of documentation that insurance was denied or lost or that rates increased because of genetic information may not be reason for comfort or complacency. Genetic predisposition to late-onset disease is not apparent, that is, the person probably has no distinguishing physical characteristic of

the trait. So people who thought that they suffered insurance discrimination because of genetic information would not be motivated to pursue legal action that would further reveal their genetic predisposition.

A lack of documented discrimination notwithstanding, more than 30 states have tried to provide legislative protection against genetic discrimination,[5] and at least 28 states have passed laws prohibiting insurance companies from using genetic information in issuing insurance or determining rates.[6] Beginning in the 1970s, laws addressing genetic issues focused on specific diseases, such as sickle cell disease.[7,8] Recent laws have addressed privacy and discrimination rather than specific diseases[5,9] by prohibiting insurance companies from requiring genetic testing or demanding results of genetic testing. State legislation, however, varies by state. Also, most people are insured through their employers, and many employers have self-funded insurance plans which do not fall under state laws. They are governed by the federal Employee Retirement Security Act (ERISA),[10] which preempts state laws and does not protect against adverse insurance actions on the basis of genetic information.

A federal solution could obviate the uneven protection among states. One federal law does, in fact, offer some protection. Although not written specifically to protect genetic information, the Health Insurance Portability and Accountability Act of 1996[11] does provide that the insured's continuing eligibility cannot be terminated by medical information, including genetic information, and that genetic mutations cannot be considered as pre-existing conditions in the absence of a diagnosis. However, this law does not prevent insurance companies from asking people to be tested or from asking for test results. Privacy is not addressed, and the law does not limit rates or preclude limiting benefits.[9]

Some are concerned that employers will deny employment to those at high risk for such

diseases as cancer which can raise the cost of insurance. The federal government, through the Equal Employment Opportunity Commission, has provided guidance that says that people with genetic mutations that predispose them to disease may be protected from employment discrimination under the Americans with Disabilities Act.[12] But this is only guidance, not law, and it has not been tested in the courts.[13] President Clinton issued an Executive Order banning discrimination in federal hiring on the basis of genetic information in February, and although this order does not directly prevent job discrimination in the private sector, it is hoped that it will serve as a model.[14]

Some scientists and legislators have suggested that genetic information should be "taken off the table" in order to prevent genetic discrimination. But the definition of genetic information, which may include family history and information other than the results of DNA testing, is ambiguous.[15] Defining the use of genetic information in underwriting as "discrimination" is problematic in a health care system that allows use of other medical information to determine rates and, ultimately, control access to health care. We already allow underwriting to make insurance more costly for some than for others; how can we draw the line at genetic information?[16] Just as having a BRCA1 mutation does not guarantee that a woman will develop breast cancer, having an elevated cholesterol or high blood pressure does not assure that a person will have heart disease. Should a person with an elevated cholesterol or high blood pressure have higher rates than someone with a genetic predisposition to disease?

What is needed? Documenting the problem before seeking an expensive legislative solution makes sense. But few objective studies have distinguished between perceived and documented adverse actions by insurance companies on the basis of genetic testing.[17,18] Two studies supported by the only company that offers commercial testing for BRCA1 and BRCA2 mutations addressed issues

related to testing and insurance. One reported the likelihood of insurance companies paying for genetic testing in a series of 363 tests, but did not gather follow-up information on the occurrence of adverse actions (loss of insurance) by insurance companies.[19] Investigators in another study documented the sequelae of testing of 57 women and 4 men. Health insurers paid for part or all of testing expenses for 29 subjects. None of the subjects experienced loss of insurance or rate increases, but the follow-up period was unspecified and probably lasted only a few months.[20] [eliminate or replace- see file with page proof corrections] It is interesting that twenty-seven of 49 subjects who tested positive for BRCA1 or BRCA2 mutations elected to have prophylactic mastectomy, and 27 of 51 who tested positive for these mutations elected to have prophylactic oophorectomy as a result of testing.] Although support for a follow-up study of these subjects has been committed, larger studies supported by nonindustry sources are needed. (Written communication, William A. Hockett, Myriad Genetics, Inc. March 3, 2000).

If insurance loss or rate increases as a result of testing positive for cancer-associated mutations are documented, and if the public has the will to address this problem, then nothing short of a reassessment of current laws or methods of paying for health care will be needed. The public debate that began in 1990's then faded from public view should be revived.[21] Whether the answer is a single payer system, community rating, laws to prevent the use of genetic information in risk underwriting, or some other solution, a fundamental change is needed in order to assure continued access to health care.

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